

COMMUNICATING TOGETHER

published by
Sharing to Learn

AS ABILITIES CHANGE

COMMUNICATING TOGETHER VOL. 12, NO. 4/DECEMBER 1995



As Abilities Change

PAUL MARSHALL,
SHIRLEY McNAUGHTON &
PETER LINDSAY

From Paul

Iwould like to welcome you to the December issue of **Communicating Together**. We hope you have noticed our new masthead, first introduced in our June, 1995 issue. We have taken its wording, *As Abilities Change*, as the theme for this issue. There is a need for new sharing to be done by us, in response to the growing population with acquired augmentative and alternative communication needs. We want to move from our previous **Communicating Together** mind-set of thinking that these alternative systems are mostly for individuals with language difficulties from birth, to a recognition that people who acquire long or short term communication difficulties through such conditions as strokes, head injury, multiple sclerosis, and Huntington's disease, need AAC as well. We believe by moving into this other AAC area, we will be able to broaden all our perspectives.

An Acquired Disability

A person wakes up in a hospital, opens his or her mouth and struggles to get a few words out. The dignity of their way of life and way of using language has changed from talking as a time filler to talking to survive! The role of provider and contributing member of society that they once took for granted becomes just a memory.

I just met Brian Pamplin, our new associate editor, for the first time this past month. When I walked into his hospital room. Brian wasn't there. He was out getting some occupational therapy. As I looked around the room I saw seven beds. This was where he spent many of his hours. As I looked, I saw a picture hanging on the wall of Brian with his wife and his son. I saw a man that you could tell was happy and fulfilled with his life. I am sure he and his son had planned to share many great times together as the years went by. When Brian came into the room, the man in the picture was still alive within him I am sure, but on the outside he was totally different.

Every time that Brian spoke it was a struggle for him. He had to store up enough air so he could communicate. He knew that we were coming and he had tried to conserve his energy so he would be able to talk with us.

A Congenital Disability

Being born with cerebral palsy, society expected little of me. You could say I couldn't fail in the "eyes" of the community! Children born in the 60s or earlier with any kind of disabling condition didn't have the same responsibility as non-disabled persons to integrate into the "normal" main stream. There are good and bad points to this. As a handicapped individual I haven't had the expectations placed on me throughout my life to measure up to the norms of society. This can allow a person to develop as an individual and not as a person being pressured to conform to the standards of his/her culture. On the other hand, if

there are no expectations and pressures by the community to contribute, then why do it?

Similarities and Differences

Let's call those who are nonspeaking from birth, Group A, and those who are nonspeaking from an acquired injury or from a disease, Group B. There are parallels that we should look at.

First, in both cases there is a vital link that both groups lack. This link is the gateway through which persons interact with the world around them. Individuals in both Group A and Group B require augmentative and alternative communication systems to be heard and understood!

Second, there is a shared learning process that needs to take place. Individuals from both groups need to learn how to communicate in the world where information exchanges rapidly. In contrast however, Group A individuals have to learn the skills to integrate *plus* the skill of communicating. They don't have what I call "a pool of living language" to draw from. Persons from Group B already have this, from years of mixing within society and interacting during many different events.



Picture a "V", one line of which represents what we can call "the handicapped life". These are our Group A individuals who can be overwhelmed with just trying to survive the daily battles. The other

line of our V represents "the normal life" of Group B, for whom the idea of living with a handicap or trying to care for a person with a handicap is a far-removed way of life. Both groups start far apart, at the top of each of the lines and are totally involved with living out their lifestyles. Both groups move down their life lines. The narrower the distance between the two lines becomes, the more each "population" begins to see and realize the needs and issues of both cultures.

When something happens to force someone into the "nonspeaking world", they go from the "normal life" into the "handicapped world". For me, it would be like getting thrown into the heart of China and starting to live without knowledge of any of the skills of that culture. I would be totally lost. I would go through a time of deep depression as I work my way through the different stages of grief. I can't even begin to imagine the grieving process that would occur when a person goes from the "speaking world" to the "nonspeaking world". The person is thrown from one side of our V to the other side in a second. There is no time to gain the skills and the support to cope. The same thing could be said if I woke up some morning and I was a normal, speaking person. We can say, it would be great! But would I know immediately how to live without being handicapped? No, I would go through a culture shock also.

As we travel the road of "changing abilities", keep in mind the two lines of our V figure. Hopefully, our articles in this and future issues will help us all narrow the space between the two lines of the "V" and inclusion for all of us can take its rightful place where the two lines meet.

From Shirley and Peter

Again, we have but to add our comments —this time, to those of Paul Marshall. We are very appreciative of the contribution of Alda Steprans to this issue of **Communicating Together**. We have Alda to thank for introducing us to Brian Pamplin, who continues as co-editor of the section, *As Communication Changes*, to Eleanor and Bruce Cornish, whose story appears as this issue's feature article, as well as to Estelle Klasner and Tara Scott, professionals working at Runnymede Chronic Care Hospital, who contributed to this issue's *Perspectives*. We are enjoying getting to know those who are sharing their experiences, "as abilities change". Alda has interacted with us and with the contributors for this issue from the other side of the Atlantic. The wonders of computer mediated communication - complemented by mail and fax! The lateness of this issue results from the additional activities of end-of-term and holidays, not from Alda's distance from us! Her observations regarding life in Latvia, which we have printed in our *Readers Write* section, provides a complementary perspective to Paul's consideration of the cultural differences between "Group A and Group B". Bringing a cultural context to the life challenges and accomplishments unique to AAC users seems to provide a comfortable and sensitive approach to the reading of Brian Pamplin's "If you don't use it, you lose it" article, Eleanor Cornish's sharing of her family's struggle with Huntington's Disease, Kari Harrington's continuation of her Skallagrigg experiences, and to the professional perspectives included in this issue - from Estelle Klasner, Tara Scott, Geb Verburg, and Tracy

Shepherd. Robert Haaf provides an exciting "*Glimpse of the Future*" which may indeed become a reality in the near future.

As we enter 1996, with the many changes to service provision that await us, we wish for you and yours, innovative problem solving strategies and continued progress in meeting the needs of those with communication challenges.

Finally, a reminder to our readers who are AAC users: The March issue is yours! Nola Millin, as editor of this special issue welcomes your ideas through comments, stories, poems, letters, articles. Mail them as soon as you can to:

Nola Millin,
3185 Forest Glade Dr., Apt 110,
Windsor N8R 1W7

or fax them to Nola 519-735-4443.

Remember, Nola needs your contributions by February 28 if they are to be included in the March issue.

§

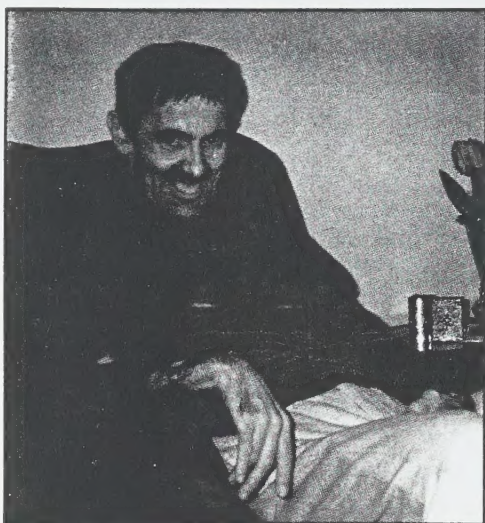
Have You Moved?

Please remember to let us know your new address. If possible, send an address label from a past issue.

Mail to:
**Communicating Together
Suite 215
3-304 Stone Rd. West,
Guelph, Ontario,
Canada, N1G 4W4**

Living With Someone Who Has Huntington's Disease

ELEANOR CORNISH
ALDA STEPRANS



Bruce Cornish

Eleanor Cornish's article has been compiled by Alda Steprans from a series of Eleanor's letters written to Alda this fall while she has been out of the country.

From Alda

There are many illnesses which affect the ability to communicate. One that I had had little experience with before I started working at Runnymede Chronic Care Hospital is Huntington's disease. Because of its individualized nature and the complex cognitive and physical changes that occur in the individuals who develop this disorder, it presents one of the greatest challenges for all of us who care for and about these individuals. How can we help them maintain their independence, express their feelings and fulfil their needs? How can we assist family members to help both themselves and their loved ones cope with all the changes in their lives?

Huntington's disease is a genetic disorder characterized by the slow degeneration of brain cells. Symptoms are individualized, but generally include jerky movements, impaired speech, dementia and eventually, death. The disease process can be as long as 20 years or more and it is truly a challenge to help these individuals so that they do not become trapped in their own little worlds, unable to communicate the most basic request or desire. Disturbances in speech production and cognitive changes begin in the early stages of the disease. In later stages the person is usually unable to communicate at all. The course of the disease is unpredictable — deficits occur randomly as the disease progresses.

This disorder affects all of the traditional areas of communication — speaking, listening, reading and writing.

An excellent source of more specific and precise information is a booklet by speech and language pathologist, Eleanor Klasner. The booklet was written for the Huntington's Society of Canada and is entitled *Managing Communication and Speech Difficulties Associated with Huntington's Disease* (1993). Although Huntington's disease does seem to present insurmountable odds, Estelle has found that some things can be done to help maintain the precious gift of communication as long as possible. Individuals with Huntington's have been able to participate in speech therapy programs and make

progress toward specified goals. As a nurse, I have found that getting to know these people as individuals and paying close attention to their body language is essential. As Estelle mentions in her booklet we must not underestimate how alert these people can be, even if they are non-verbal. The tiny smiles, little laughs, the twinkles in their eyes have confirmed how true this is, over and over again.

Introducing Eleanor and Bruce

I have gotten to know many wonderful people while working at the hospital. Mrs. Cornish, who has written the following article about her family's tragic experiences with Huntington's and her son Bruce, is one of them. Mrs. Cornish seems tireless in her energy to care for others. Until I started to write this article I never knew of the other family members she has looked after over the years. She was able to care for them in her home. Bruce has a most extraordinary sense of humour. I know it has helped him to cope with the many things he finds he can no longer do. His continuous struggle to do all that he can for himself remind us of his unique nature and has been an inspiration to me and many others. It has also helped those who have grown to know him be better care-givers, better residents, better friends. I am only sorry that at this time, his communication skills are not good enough for him write an article for us.

From Eleanor

It is very sad to see your loved ones become increasingly more ill, more dependent and know that you cannot do anything to change that.

When my youngest daughter first got Huntington's disease, we had never heard of it before. She was in the hospital for three weeks before she was diagnosed. We watched her gradually go downhill for about 20 years. She was 19 when the diagnosis was made and she died at 37. My other daughter kept saying that she had it, too. She was so afraid of getting it. I think that perhaps that is why she only started having symptoms when she was 30 years old. She died when she was 46.

The disease is different for each individual. My husband wasn't actually diagnosed until he was 60. There were no symptoms of it and we didn't know too much about the disease, then.

Now, my son Bruce has Huntington's. The doctor first suspected that he had it ten years ago from the symptoms he had. He has had a hard time with it. He wanted to work so badly! He dragged himself to work every morning until he came home one day, practically crying, because he had been fired. These are the things that are hard to take and without my church and friends and faith in God, I could not have carried on.

Changing Communication

It is very difficult to communicate with someone who has Huntington's disease. The ABC board Bruce has is very helpful because he can spell. My daughters did not have this tool and so it was much more difficult. The deterioration in communication is really very distressing as it becomes more and more difficult to know what the person is thinking. It

is very hard for the people with Huntington's to express their thoughts. Their speech makes sense to them, but to anyone else it is just a muffled sound and it becomes hard on anyone trying to carry on a conversation. Rather than repeatedly asking the same question it helps to change the topic. When Bruce is at home and trying to tell me something I cannot understand, I sometimes put on a funny tape which he enjoys.

The change in communication does cause a deterioration in family life, because there is always a tension in case you say or do the wrong thing.

The change in communication does cause a deterioration in family life, because there is always a tension in case you say or do the wrong thing. It was very difficult when I had Bruce and his sister at home, when neither of them could talk. Maybe for me it was a little more difficult, because I had no one else to talk with. My whole family had Huntington's. Some families have two or three members that are unaffected, but all of my family had it.

As Abilities Change

Bruce was admitted to the hospital when I developed pneumonia and could no longer care for him. I had tried very hard to keep him at home. At first, Bruce was very upset and could not settle in, but now he has and I think he realizes that I cannot handle him at home. With him in the hospital I can relax when I get home. When he was at home I tended to get

a little upset at him and that was not good for either one of us. I bring him home or to the Huntington's Society one day a week. I think that at the hospital they do everything they can to make him comfortable. He is doing pretty well lately and is in a good frame of mind. He laughs quite a lot and seems more settled than before.

What I think is most important is:

- 1) Treat persons with Huntington's disease as normal people, not as though they do not know what you are saying.
- 2) Persons with Huntington's disease need lots of extra food (calories), because their system is always working and using up energy. Even when people who have Huntington's sit or lie down they do not relax. Parts of their bodies are always working and using up energy.

It would be nice if persons with Huntington's disease could be taken on bus trips or some outings. Maybe their family members could go with them and help.

A person has to take a lot of time to see what a person with Huntington's wants or needs. When persons with Huntington's disease get angry, it is usually because they cannot make someone understand what it is they want and they get frustrated. Don't forget, they have been used to doing things themselves. It is very frustrating having to ask someone to do something.

§

Kari's Skallagrigg — Part Three

KARI HARRINGTON



Kari continues with the third instalment of her search for Skallagrigg. This time we discover who her Skallagrigg is.

Who is my Skallagrigg

Now, I know that I have a Skallagrigg. I told my friend Kathy this. She told me that it has to be my own Skallagrigg and I should think of a name for it. I realized that was true. I looked around. I couldn't just pick one — it couldn't be just anybody. It had to be Somebody who cared about me. Kathy or Sharon? Yes, they do care about me, but there's more about my Skallagrigg than just caring.

My Skallagrigg is believing in me to pull myself through my problems. It took me a couple of days to figure out who my Skallagrigg really was. Finally it hit me. Like Arthur's Skallagrigg, mine is a member of the family. I went through all the good, happy memories when I was with this person. She loved and cared about me so much. She also believed in me, in whatever I did. I remember

one night I was watching Grandma rug hooking. I asked Mom if I could try rug hooking myself and she said that she didn't think so. I needed two hands. How would I ever put the wool around the hook without pulling it right through? My Grandma said, "Oh let her try it." So Mom bought me a rug hooking set. It took me two whole hours to get the first two pieces of wool in, but I did it. I got faster at it as time went by.

My Skallagrigg is believing in me to pull myself through my problems.

Here is another memory that is important to tell you about. Our first dog, Heidi, had six puppies. Grandma kept one and called her GG (which stood for Great Grandma). Anyway, I just got off the bus one day and the front door was closed so I went to the back door to let somebody know that I was home. Of course Heidi and GG were in the backyard, so even before I got to the door, Heidi jumped on my lap with her paws on my shoulders licking me to death. GG was still a small puppy so she had trouble jumping up, but she finally got up. Now I had two dogs on top of me. They pushed me over and knocked my glasses off. Finally I pushed them off. GG decided to chew on my glasses which were on the ground. Here I was hanging over the side of my chair and couldn't sit up and a small

puppy chewing on my glasses while the other dog tried to get up on me again. I started to cry hoping somebody in the house would soon rescue me. It was Grandma who came out and rescued and comforted me.

Grandma stayed with us every fall and winter and went back to her cottage in Stayner for the spring and summer. I remember one time when we took her back to the cottage, I felt sad to leave her behind. It had to be lonely in that cottage all alone.

Yes, it has to be the only Grandma I knew. It's got to be her. It all makes sense with these memories and a lot of the others that come in to my mind. Here is a poem I wrote for my grandma a few years after she passed away.

To My Grandma

*I'm thinking of you,
The happy times
we had together.
The times you stayed with us.
The walks we had together.
The visits we had
when you went home.
You were there to cheer me up
And told me
everything will be alright.
You believed in me,
in whatever I did.
I'm thinking of you.
The bad times,
I don't want to think about,
Only the happy memories.
So if you can hear me,
I just want to say
That I always loved you
And I always will.*

Now you might be wondering why I thought of calling my Skallagrigg, 'Lillunau'. First of all, the name 'Skallagrigg' is unusual, but at the same time, it sounds a perfect name for someone like God. I wanted to have a name like 'Skallagrigg' for my Skallagrigg. My grandma's name was Lillian Lunau - Lil, for short. After thinking about it for a while, I put both of her names together and came up with 'Lillunau'. It looks and sounds like the name of a very special, important person. Later on that evening, I finished reading chapter eighteen in *Skallagrigg*. As I was reading that Esther's grandmother finally accepted and loved her, I knew the end of that chapter was telling me that I was absolutely right about who my Skallagrigg is.

I could easily let this story turn into a book as it's much longer than I expected it to be, but for right now I'll just sum things up. I think I always had a Skallagrigg - different ones over the years without knowing it. It wasn't until a month ago when I started to read the book for the second time that I really believed I had a Skallagrigg - Lillunau. My teacher came to my room to work on my creative writing course one day. I couldn't think about that, or anything else as a matter of fact. I had to start to write this story as the belief of Skallagrigg was getting so strong — so strong that I couldn't control my emotions. I practically burst into tears when my teacher said I could do this story for a school project. After Kathy plugged me to the heating pad and got me all

comfortable in my chair, I began to write. My smile slowly came back and I knew my uncontrolled emotions were no longer exploding.

If you really think about it, I bet you have a Skallagrigg too, either it's God or Jesus or someone like Arthur, in the book that I have. This is the first spiritual experience I have ever had. Arthur's Skallagrigg was somewhere out there, alive. Mine is more like a spirit because she is. Although she is up above in heaven, Lillunau always comes when I call her. I know she's always watching over me because even when I can't call her for help, I can sometimes feel and hear her. It absolutely amazes me when I can actually see her face up in the sky.

Thanks Lillunau. I know I can always count on you for helping me to get through the hard times in my life.

§

AAC: AUGMENTATIVE AND ALTERNATIVE COMMUNICATION

*The Official Journal of the
International Society for Augmentative and Alternative Communication*

Editor: **David R. Beukelman**, Professor of Communication Disorders,
University of Nebraska, Lincoln, NE. 68583-0732, USA

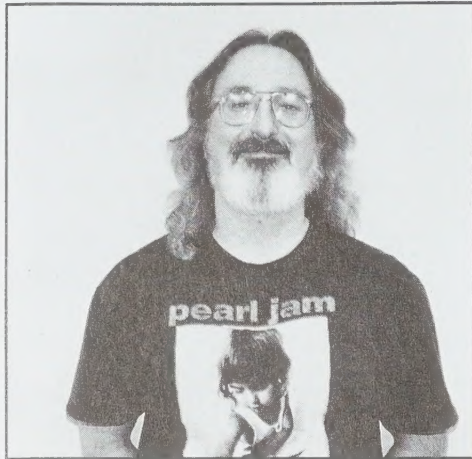
International in scope and transdisciplinary in approach, AAC presents **articles, case studies, position and research papers, conference abstracts**, with direct implications on program development, assessment and intervention. A journal that stimulates development and improves service delivery in nonspeech communication.

Quarterly/\$70/year personal/\$110/year institutional (U.S. funds)
(add \$20/year to subscriptions outside U.S.)

Mail to: Decker Periodicals Inc.
P.O. Box 785
Lewiston, N.Y. 14092-785. USA

A Glimpse into the Future

ROBERT HAAF



As another year of *Consuming Technology* draws to a close, and a new year begins, I want to take this opportunity to look ahead, and to talk about what the future may hold. The last two instalments dealt at length with the limitations and disadvantages inherent in present AAC technology, and I feel strongly that these issues need to be discussed and addressed by all stakeholders in the process. However, I now want to begin to approach the situation from the *other* side, to demonstrate where existing technology might lead AAC consumers and professionals, now and in the very near future. Actually, these topics are, I believe, very consistent with the overall idea presented over the last two issues: Existing mainstream computer technology offers advantages to the AAC user far beyond those of existing “special” AAC technology, advantages that can easily be viewed

as *communication*, that can be integrated with voice output and writing applications, and can serve to enhance the abilities and the independence of AAC users.

Digital Media

The topic I would like to talk about in this issue is one that’s been with us for a while now: *Digital media* — the availability of traditional reading materials on computer platforms. Over the past few years, several technologies have developed to the point where their use in providing comprehensive reading materials on disk is now realistic and affordable. The advent of the CD-ROM has allowed disabled individuals to access educational reference works (and even some leisure reading) much more independently than they could access traditional print. As prices plummet, the use of scanners with optical character recognition (OCR) software becomes more feasible, allowing anyone with a computer system to “digitize” printed material with the original text and graphics intact.

However, I don’t want to imply that these technologies at present are perfectly suited to the disabled user. CD-ROMs offer a wealth of information, but usually the needs of the disabled user are not often considered: fixed font sizes, hierarchical menus and controls designed for rapid use of the mouse are still common with such software. When using scanners, the typical result is to simply “digitize” an existing book or magazine, ending up with pages and pages of text (and some pictures) on a

computer screen rather than on paper. This is often what people envision when they first think of “digital media”. While this is certainly possible (and can certainly be useful), given the potential of the technology it’s far from the most desirable solution: the material can be read in this form, but it can’t easily be *controlled* in a functional way. Digital media can now easily be crafted to provide any user with flexible and dynamic control over large amounts of information. This is its strength because there’s nothing inherently better about reading something on a screen as opposed to on a page. Ultimately, it will be necessary to provide this type of control if disabled individuals are to use such digital media productively.

My point here, then, is twofold: Since they offer increased independence and opportunity to the disabled individual, access to these technologies as they exist now is important for educational, vocational and leisure pursuits. However, now perhaps is the time for clinical professionals and hardware and software developers to begin utilizing the potential of these technologies to meet the needs of those who have the most to gain.

A Digitized Communicating Together

To get a better idea about what digital magazines and books *can* offer individuals with disabilities, why not consider a publication that is geared towards AAC consumers? Let’s take a look at what I think is a “natural” example — **Communicat-**

ing Together on disk! For this demonstration, please remember that **Communicating Together** is not actually available in this format (not yet anyway). I spent some time putting text and graphics from a representative issue into an interactive “shell” to show how a digital **Communicating Together** might look and feel, and we present some examples of this on page 10.

When the digital version of **Communicating Together** is loaded onto your computer, the program opens to the *Table of Contents* for the current issue. All of the information that is available in the traditional format would be available here (and possibly more, as we’ll discuss below). Clicking on any of the articles in an issue will take you directly there. It is important to realize however that digital media do not restrict the reader to moving in a linear way through the articles or any other information. Possibly the major advantage of a digital magazine for any user is the use of *hypertext* — interactive “hot spots” in the text that allow you to click on them to move immediately to the relevant topic. So, if you’re reading the editorial and something seems interesting, you can click on the text where it is mentioned and go directly to it.

While the advantage within a single issue might not be immediately apparent, at the end of each year an “archive” of a complete year’s issues could be available. That is, all of the issues for that year could be electronically linked together and accessed as easily as a single issue. This *would* provide specific advantages: links to articles in past issues could be followed up immediately, so readers could follow topic “threads” throughout multiple issues, read all of **Consuming Technology** for the year without

having to dig out past issues, or in fact do whatever they like. Hypertext allows readers to easily make their own “path” through the information that is available, according to their needs, interests, or preferences at the time. Many feel that this is the most significant advantage that multimedia conveys, even beyond the availability of different types of media on disk or CD-ROM.

Digital media can now be crafted to provide flexible and dynamic control over large amounts of information.

Multimedia

Speaking of multimedia, while the example of **Communicating Together** presented here only contains the standard “media” (text and graphics) that are available in the traditional hard copy format, there is of course the potential to include other digital media. Imagine Shirley McNaughton being able to include animated graphics in *SymbolTalk*, or guest authors including recorded sound files or even video in their presentations! All of this is now possible with the technology we’re talking about.

The advantages of digital media outlined above could of course be beneficial to *all* readers of **Communicating Together**. However, more to the point of this article, a magazine available in digital form also offers unique advantages for the disabled reader, who ideally needs to be able to move through written material independently and with as little time and effort as possible.

The first and most obvious advantage is *access*. Most of you reading this are aware of the large

number of hardware and software products that allow most AAC users to emulate the keyboard and mouse on any computer platform. Our hypothetical **Communicating Together** “shell” could also come with (for example) customized *KE:NX* and *ClickIt* files on a Macintosh, to allow the user to get at the controls more easily. Digital media can also be manipulated to compensate for sensory limitations: larger fonts, visual enhancements (such as coloured highlighting boxes around hot spots), spoken labels as you scan through the *Table of Contents* or navigation controls, speech feedback, or even complete audio for articles could all be incorporated into this format. Combined with the flexibility of digital media, these options make this technology undeniably powerful for any AAC consumer.

After reading this description, perhaps some of you may be excited about the potential that it offers. Well, let us know! Shirley, Peter and the Associate Editors of **Communicating Together** have always been committed to making the magazine accessible to everyone. Maybe down the road, if enough people see and express the need, my digital **Communicating Together** example could become reality. As always, I look forward to hearing from you.

So what else is down the road?

OK, then, how about a *Sharing to Learn World Wide Web Page* on the Internet, where STL publications could be previewed and purchased, **Communicating Together** could be subscribed to and downloaded, and links to dozens of other Web Sites related to communication, technology and disability issues could be maintained? I promise that we’ll talk more about this in the new year.

§

Communicating Together in the Future



First choose (click on) the issue you want to see

Paul's Place

Paul Marshall



Welcome to Paul's Place! Let's share together. It is my hope that this column will not be the work of one person but a groupwide effort. The important thing is that we are together. I look forward to a section that is overflowing with ideas on many issues concerning communicative communication.

Please keep in mind when reading Paul's Place that my ideas and point of view come from the experiences and problems I have faced in my life and here I have personally dealt with them. So forgive me if I get lost in my own culture. Communicating Together is read in over thirty different countries, each having its own way of life. My goal is that we will start to break down some of the misconceptions regarding superlative forms of communication and the barriers that non-speaking persons face on a daily basis.

A little history about myself: I am from a small farming community in Southern Ontario. Throughout my childhood I developed and became aware that the world had to be won on the inside. The more I walk through this life, the more I believe it to be true. As my two older brothers and I read at the Farmer's market with our parents, I can remember my first lesson as people stared and thought (couldn't think for myself).

2 ▶



Welcome
It is my
work
The i
look:
with:
ment

Please
Place
from
faced

dealt with them. So forgive me if I get lost in my
gether is read in over thirty different countries, e
goal is that we will start to break down some of t
tative forms of communication and the barriers tl
daily basis.

Choose (click on) the article in the issue from the table of contents.

Decide on how big you want the print.

Teaching and Learning

As Abilities Change, Does Communication?

TRACY SHEPHERD

Tracy is a speech language pathologist at the Augmentative Communication Clinic in the The Children's Rehabilitation Center of Essex County, near Windsor, Ontario. Here she discusses some of her experiences with individuals who lose their ability to communicate in adulthood. Her infectious enthusiasm and optimism for her work is clearly seen in her writing.

Over the last few years of my career as a speech language pathologist in an Augmentative Communication Clinic, I have had the pleasure of working with a number of individuals who have had the misfortune to lose their communication abilities in adulthood. These clients are most enjoyable to work with for many reasons. The most important reason to me (and I hope to them) is that I feel I can make a real impact on their lives in a fairly short period of time. Often times, after only one visit, a clinician can offer communication alternatives and suggestions that allow interaction to continue in a modified way. Enabling a husband and wife to communicate with each other again has put many smiles on their faces and mine. In some instances, maybe the change only lasted for a short time due to the nature of the disability. However it is priceless to families in these cases to have the last memories of that loved one include the sharing of thoughts and feelings.

In many cases the communication options have involved technology. I am certain that anyone who uses augmentative communication can attest to the frustration of relying on technology as their lifeline to the outside world. Those of us using any form of electronics can relate on a smaller scale. For example last week, I was sure I set my VCR to record "Friends". It failed and I missed the best episode. Likewise, can you really watch one channel while taping another? And how long does it take you to change the clock after daylight saving time kicks in?

One of my biggest fears is having my client or his/her facilitator call me the Thursday or Friday afternoon before a long weekend with the cry of "The @#\$%• thing ain't workin'!" These calls often leave myself and my colleagues scrambling to get a system of some sort in order while the client's device is taking the long weekend off. Many times clinicians are seen jumping on the road with a replacement *Lightalker*™ for a client whose device "caught the flu". This shows the importance of having a low tech back up system. Although low tech devices may not have all the bells and whistles of the new technology, they will offer a means to an end in the case of difficulty.

Many of my stories do not have "happily ever afters" since, for the most part, the clientele I am referring to have degenerative neurological conditions. But there are pleasant outcomes, if only for a short time. Working closely with families dealing with such situations also provides us with tremendous insight into what our clients are dealing with on a daily basis. I feel I have really

grown as an individual from my experiences with these people and I am grateful to them for allowing me that opportunity.

Although the situation is far from ideal, offering families and clients the power of communication when they need it most is very rewarding. Allowing an individual to live independently and direct his own care has also been a goal which has been achieved for one of my clients. A 33 year old man came to our clinic with a diagnosis of Lou Gehrig's disease (ALS). I remember he was very concerned about being able to communicate with his six-year old daughter. My heart went out to him. This was one of my first experiences with this type of client and I put everything I had into it. His occupational therapist and I must have shown this man and his family every augmentative communication device available on the market. In fact, we probably overwhelmed the poor guy but we were determined we could find a method for this man to communicate. And we did! He learned Morse Code and has been using it successfully for almost four years now. He is able to talk to his daughter and other family and friends. He is able to tell us off-colour jokes when we go to visit him. And most importantly, he is able to live independently in an apartment and direct his own care. He has workers coming in and out at key times during the day to assist him, and he is able to let them know exactly what it is he needs. I believe he is also writing a book. A success story, until his device breaks down of course.

On another case, I was out to an initial home visit with an elderly

couple (I'll call them Pam and Bill). Pam was in the later stages of Lou Gehrig's disease (ALS). Bill had heard of our service and made the referral. Upon greeting this delightful gentleman and his wife I began to investigate how they were getting along communicating with each other. Pam had barely more than a whisper to her voice on a good day. Her husband explained how he could understand her, and read her lips to catch her meaning. After pulling out a few low tech options from my bag of AAC tricks I gained some rather valuable information from Pam. She made me aware of her husband's hearing loss, for which he would occasionally wear his hearing aids. I immediately saw her frustration and realized a device with projection and

a clearly audible voice would be invaluable in this situation. Remember the funny look on Pam's face when Bill was initially explaining to me how well they were communicating. It wasn't until I had the full story that I realized the look clearly stated "He's not understanding me!".

Unfortunately, Pam was only able to make use of the voice output device for a very short time. I hope that some of the strategies I taught the two of them helped them out in their last times together.

Recently working with another family, one of the greatest rewards I received was to have Frank's granddaughter, Jenny, who was five years old, have a conversation with her granddad. Frank had been struck with a disability that manifests itself much

like Parkinson's disease and his voice had been gone for as long as Jenny could remember.

The little niceties that technology allows go a long way. We all would like to pitch the computer out the window when the screen freezes up in the middle of a presentation. Even so, let's try to keep optimistic and remember all that technology has allowed for our clients before the device 'gets iced up' (to coin a phrase used by one of our youngsters).

I have asked two of my clients to share with you some of their trials and tribulations and share their feelings about how technology has affected them as their abilities change.

Living with ALS

I'm a thirty-five-year-old guy who unfortunately has A.L.S.. The disease has no cure, with many diagnosed cases only having the life expectancy of a couple of years. I've been living with it for more than twelve years. With the help from the Children's Rehabilitation Center of Windsor, I was able to obtain a laptop computer with a voice synthesizer system to help me communicate. The Alhambra society purchased the system for my use. I don't know what I would do without it. Since the first day two years ago, it's made big difference in my life.

A.L.S. is a neuromuscular disease that in time renders you almost helpless. In my case my speech has been affected due to the lack of muscle I have in and around my throat. Henry and Betty Chouinard have been long time members of the Alhambra society. When they were told I'd eventually have trouble communicating, they and the other members decided to purchase my system. My brother Joe contacted Tracy at the Children's Rehabilitation Centre and within six months I had my new way of communicating. I operate the system through the Morse code touch pad, which I hold in my hand. I would encourage any individual who is unfortunate enough to have a disease, such as the one I have, or anything that would require the services of places like the Children's Rehab Center, and various other organizations that are out there, don't be afraid to ask for help. These places are in almost every city.

John Wilkinson
Windsor Ont.

Parkinson's Disease

I was diagnosed with Parkinson's in 1987. My writing was the first to go, and then I slowly started to lose my voice. It just got weaker and weaker until essentially I had nothing more than a whisper, which got weaker as well. This made it hard to communicate with friends and family, and over time they stopped trying. Even my grandchildren had never heard me talk. Then I heard about the Children's Rehabilitation Center. Tracy came out to the house to do an evaluation and brought several machines with her that might help. I chose the Lightwriter because of its size, the printed screen for people to read my message but also the spoken voice. Now I can talk to my wife from another room instead of my wife putting her ear up to my mouth to hear me. My grandchildren love to talk to me and I even sent a telephone message to my daughter in Switzerland. The Lightwriter has been a godsend and I am very grateful for modern technology.

Keith Ebbinghaus
Essex, Ontario

Many thanks to Keith and John for sharing their thoughts and all the best in the future.

Tracy Shepherd

§

Maintaining communication

ESTELLE KLASNER

Estelle is the Director of the Communications and Swallowing Services at the Runnymede Chronic Care Hospital in Toronto, Canada. She has worked with Brian Pamplin, author of the As Communication Changes section. We are very pleased that Estelle has shared her insights in this article.

Individuals communicate for a variety of reasons. One reason that individuals communicate is to exchange ideas and information. Another more important reason is to stay connected to others on a person-to-person level. We share thoughts, wishes, dreams and hopes through communication. When verbal communication skills become impaired or are no longer available, the reasons why we communicate still remain.

How might we maintain communication in the face of deteriorating illness? The actual techniques vary as much as the individual. What is important to establish is a few general rules and beliefs that both communication partners share.

1. Control

Rules about how the communicative exchange is controlled are important to establish early on. It is essential for the communication partner without difficulty to constantly make sure he or she is not

controlling and directing the whole conversation. Both people must act as partners participating equally in the interaction. The need for control in conversation was clearly demonstrated by the following interaction:

The husband of one of the patients I work with related that before her illness, his wife wanted to maintain control of everything. She often even finished sentences for him and reinterpreted what he was saying to others. As her speech deteriorated, the husband found himself finishing her sentences and explaining to others what her message was. One day his wife looked at him and said with all the energy she could muster "I don't know how you stood it for all these years. I want to talk for myself and probably so did you." She then began to cry and the issue of control was able to be discussed in an open frank manner and some ground rules were able to be laid.

2. Time

Allow enough time for the conversation. Because one person has difficulty with verbal communication, the interaction will most likely take longer than expected. Allowing enough time for communication often means the difference between a successful conversation and an unsuccessful one. Residents in long term care facilities are always saying that staff are "too busy to talk" and

therefore do not initiate conversation. Many of my clients are heard beginning conversations with hurried family members "I know you are too busy to talk to me, but . . ." Allowing enough time also communicates interest and importance for both communicative partners.

3. Responsibility

How responsibility for communicative success is handled is also an important issue to consider. The individual without communicative difficulties must be prepared to facilitate and assist the individual with difficulties in a dignified and acceptable manner to the person with difficulties. It is a difficult job to take added responsibility for the conversation without controlling it, but this is essential so that all sides can be heard equally. Many clients have personally communicated to me that they feel a great sense of relief when the other partner will assume responsibility for communicative interactions so that they can be successful.

With a few simple ground rules, communication can stay alive and well for a very long time. §

Different Therapeutic Focuses

TARA SCOTT

Tara works as a communication disorders assistant at Runnymede Chronic Care Hospital, Toronto. Her primary role is to implement speech and language therapy programs under the supervision of the speech/language pathologist. She is involved in both individual and group therapy.

Many of the patients I see suffer from degenerative disorders such as multiple sclerosis and Huntington's disease. All of them communicate verbally with differences in ability.

In my experience with multiple sclerosis for example, sometimes an individual will run out of breath before he or she has completed message, leaving a trail of mouthed but not voiced words. Face-to-face, the listener can often use the context or read the speaker's lips to fill in the missing words. Over the telephone, however, the message is incomplete. As communication abilities change,

so do the strategies necessary to maintain effective oral communication.

When one lady with whom I work first came to the hospital, her voice was whispery and quite inaudible. We began work on respiration and voice exercises to improve her breathing techniques and the loudness of her speech. This therapy is an ongoing process but she is now much more aware of planning the speech process. She also evaluates her speech while speaking in order to maintain an adequate speaking volume. This lady can now communicate effectively with family members, the nursing staff and personnel in the other therapy departments.

The groups with which I am involved have different therapeutic focuses. The first, an opinion/survey group, concentrates on the development and use of interactive communication skills. This group provides the members an occasion to come together once a week for one hour, to engage in a group discussion of current and interesting issues.

One participant who suffers from Huntington's disease uses an alpha-

bet board to supplement his verbal communication. I encourage him to provide yes/no and short responses verbally. For longer explanations, he spells his message on the alphabet board while I read it to the group. In this way, this individual, who has much to share, can provide long and detailed opinions just like anyone else in the group.

The second group, a novel group facilitates communication, interaction and reading comprehension skills. This group, which also meets once a week for one hour, gives the members the opportunity to read aloud and openly discuss various reading materials.

For one individual with multiple sclerosis, if his book is resting on the table, others have great difficulty hearing him because he lowers his head and talks into the book. Yet he has difficulty holding the reading material steady at eye level. To solve this problem he now uses a bookstand, raised to eye level, that support the book for him. This serves to improve his posture and enables him to adequately project his voice. §

COMMUNICATION OUTLOOK

FOCUSING ON COMMUNICATION AIDS & TECHNIQUES

COMMUNICATION OUTLOOK is an international quarterly magazine which documents and celebrates augmentative and alternative communication.

To receive a sample issue and subscription form, send this ad to:

COMMUNICATION OUTLOOK Subscriptions,
405 Computer Center, Michigan State University,
East Lansing, MI
48824-1042, USA.

Join ISAAC Now

The International Society for Augmentative and Alternative Communication (ISAAC) offers members reduced rates for: **Communicating Together**, **Communication Outlook**, and **Augmentative and Alternative Communication (AAC journal)**.

For a membership application or other information about ISAAC, write:
ISAAC, P.O. Box 1762,
Station R, Toronto, Ontario, Canada, M4G 4A3.

AS COMMUNICATION CHANGES

If You Don't Use It, You Lose It.

BRIAN PAMPLIN



Brian Pamplin with friend and co-editor, Alda Steprans

You will remember Brian from our last issue where he wrote about the quality of care in a chronic care hospital. Here he discusses how others are adapting to his changing speech capabilities. In the article that follows, Alda Steprans talks about how important it is for nurses to communicate effectively with their patients, even those with severe communication difficulties.

The biggest problem I had when I came to live in the hospital was my speech. My speech deteriorated. The nursing staff was so used to patients not communicating, that some nurses did not expect me to communicate, so I didn't. The muscles I used for speaking became weaker, as they say "If you don't use it, you lose it."

I speak to residents who react positively to me in some way when I talk to them.

I found that the other patients did not speak to me and because of that, I didn't speak to them either. I talk to them more now, but I am fairly selective about whom I speak to. I speak to residents who react positively to me in some way when I talk to them. As I have gotten to know the residents, I know who will let me finish a sentence. That is a big deal to me.

I have become more aware of my own problems communicating. I am just learning as I go along. I have gotten to the point where everybody, including most of the staff, lets me finish a sentence. I think they all realize that I am having a problem so they let me finish what I am saying. I am not sure how that change hap-

pened. I find now that sometimes I talk to other patients whose speech is worse than mine because I know we help each other.

I found that speech therapy really helped me because in those sessions I had to speak to the therapist. Just talking helped. She also put us into a group which consisted of other MS patients who had difficulty communicating. I found that the group helped me to understand that other people have problems similar to mine.

My family is also learning that I am having a problem with communicating. They let me finish my sentences. That is the most important thing to me. I have seen a change in my cousin. Now I have got him letting me finish my sentences. I think that in general, people around me have become used to my communication problems and give me more time.

When I was very sick recently, my speech became very weak. That did not bother me so much because the nursing staff were good at anticipating my needs. I think that is because they are getting to know me as much as I am getting to know them.

I think my communication skills will become worse. I am not particularly sorry for that. I have enough other things to worry about. In the meantime, talking itself is the best therapy.

§

When Communication Fails

ALDA STEPRANS

I am thrilled and excited about having this opportunity to share my views about communication and what happens when communication changes. Most of the readers of this magazine are very familiar with the problems that arise as the result of the inability to speak. The inability to speak affects not only those of you who have cerebral palsy, but also many people who have chronic illnesses such as cerebro-vascular accidents (CVA or stroke), Parkinson's disease, multiple sclerosis, Alzheimer's disease, and Huntington's disease. In many cases the ability to communicate may be improved with the assistance of speech therapy and the use of aids, such as computer technology and letter boards. In other instances, the ability to communicate continues to deteriorate as the disease progresses. The only things that are certain are that each individual's course is different and that communication is an important tool for keeping related to the world around us, for expressing who we are, our ideas, our feelings, our wants, needs and choices.

Working in a Chronic Care Hospital

I am a nurse and have worked in a chronic care hospital for almost ten years. Nursing is an extremely intimate profession. This is one of the elements that I enjoy most about it — it brings me close to other human beings. The nurse's role is to help her client achieve the highest

possible level of health, physically and mentally, and to provide comfort. I have always been awed by this responsibility.

Having read **Communicating Together** for several years, I have become familiar with its writers and have always been impressed with what they have to say. Much of what they write is relevant to all people who have difficulty talking. Many of these people, for example the residents I work with who cannot speak with ease, have little opportunity to express themselves. I believe that this magazine could help many people who have difficulty talking, as well as their families and those who care about them, to better understand how to help those who have difficulty communicating orally. It is always good to know that others share some of the same feelings, fears, and experiences. It is also interesting to see that some of your thoughts and ideas are unique, but that you feel so confident about yourself, that you can share them with others. This magazine makes room for many different opinions.

Congenital Versus Acquired Communication Disabilities

Are there concrete differences between people who are born with an inability to speak, and those who lose the ability later in life? What are the similarities and differences? In the hospital where I work, only one in five residents communicates effectively. This presents a tremendous challenge, in the sense that it is communicating with the resident that permits a nurse to assess whether any intervention in care is necessary and if that intervention has been

successful. How does the nurse know whether her non-communicating client is comfortable or happy? How does the nurse help the person who cannot express feelings, needs or preferences verbally?

Body Language

Effective nurses communicate with nonspeaking clients as well as with speaking ones. One of the most important aspects of nursing those who are nonspeaking is to be very sensitive to their body language. This language has not been well researched and is probably unique to each individual. Nonetheless, as the sensitive nurse comes to know and care for the client, this nurse will often sense that the person being cared for is uncomfortable, unhappy, cold, or ill.

What is it that gives the nurse these clues? There may be overt changes in behaviour, such as moaning, groaning, hitting out, or thrashing. Or slight nuances such as increased respiratory rate or restlessness, decreased alertness, an unusual utterance, or even some unusual movement of an arm or leg. These more subtle clues however, are only interpretable by a nurse who knows the clients well, and therefore, can pick up these often intricate behaviours. The nurses who care for and work with this population over a long period of time, are often exceptional at their ability to pick up these cues.

In this edition of **Communicating Together**, Brian Pamplin points out that, when he was very ill and could not speak much, he did not feel terribly worried about not being able to express himself, partly

because the nurses were good at anticipating his needs. Since Brian has come to live in the hospital, nursing staff have tried to find out about his preferences, his habits, his special needs, so that now, when there are times that he cannot express them, many nurses are able to anticipate them for him. This also implies that those nurses care about Brian enough to foresee them, remember them, and try to fulfill them. I have been very fortunate to work with people who care about the residents' needs in more than just a superficial way. When nurses notice some unusual behaviour in a nonspeaking resident, they often intervene in some way. They may draw a blind so that the bright sun does not shine in the resident's eyes, put an extra cover on, move the resident to a quieter location, or to a more active one and then watch whether the intervention is successful in changing the unusual behaviour. Nurses who work with those who are nonspeaking will also often check with each other, with family members, or with neighbouring residents, to see if anyone else has picked up on changes in the resident's actions. Because the changes in behaviour are often subtle, it is difficult to be sure whether one is being oversensitive and simply imagining them. It's good to get feedback.

Having done some research at the hospital over the last few years, I have become even more aware that:

1) *People* — hospital staff, visitors, and other residents, speak far less to those residents who do not communicate verbally than to those who do speak. After spending considerable time trying to overcome this problem, I have also become more conscious of how difficult it is to keep up a conversation with someone who does not seem to respond. It is

hard to know whether that person understands, or if small talk is annoying to that person. Again part of the key is to be sensitive to the body movements of the resident. What behaviours does the nonspeaking person exhibit as you talk? Does the person stay alert? Is there any change in body movement? I think that the worst error one can make is to assume that the person who does not respond does not understand. The caring nurse will tell the resident, even one who seems totally unresponsive, about what she intends to do for him and will tell the person she cares for about what is happening in the world, will share with him those things we all feel are important. This does become easier to do with practice. It is important to encourage visitors to speak to those residents who do not seem to understand.

I think the worst error one can make is to assume that the person who does not respond, does not understand.

2) *Touch* remains an important aspect of communication and has not been studied nearly enough, but nurses know how critical a communication tool it is. Those who care for the severely chronically ill are in frequent physical contact with them. They know that

through this contact, they express much about the relationship between themselves and their clients. When a nurse touches a client gently or perhaps takes the resident's hand before a clinical intervention, the resident knows that a caring person has approached. When a nurse washes a client with tenderness, that person knows that he is respected as a person. Although more research is being done in this field, we have a long way to go before we will understand the true significance of touch.

3) We often assume that *we know how a chronically ill person feels*. The majority of people assume that chronic illness is a tragedy and that life in a chronic care hospital must be miserable - and indeed this is sometimes the case. However, in a study I recently did on "Quality of Life in a Chronic Care Hospital" I, myself, was surprised at how well many severely handicapped people have adapted to their illnesses, to their lives in an institution. Many of them feel that their quality of life is good. Each individual I interviewed considered different aspects of life to be important. It was this uniqueness that reminded me of how important effective communication is between people. It is listening to another's preferences and choices that helps us assess what is critical in improving that person's quality of life.

§

Rehabilitation as Self-Service

GEB VERBURG



More than once, some might say, once too often, I have in these pages voiced my concerns about the inappropriateness of the typical medical model for rehabilitation services. Occasionally, I have expressed the belief or hope that rehabilitation services, by nature of being so different, could evolve a model that would guide medical service provision itself.

ECART

In October of last year I attended a conference (European Conference for Advanced Rehabilitation Technology, ECART) at which a review of Europe-wide rehabilitation services was presented by Dr. Lucas Witte of the Institute for Rehabilitation Research in Hoensbroek, The Netherlands. In the course of that presentation, of a very recognizable or typical rehabilitation service model, an idea occurred to me which I have since discussed more widely and want to present here.

At ECART, where I proffered a still poorly-formed version of the idea, it caused some concern. There are indeed aspects that are very threatening, even more so than the notion of empowerment has been. I think that the idea belongs in this issue because it addresses what I see as a major need in the community at the moment. A need that flows, firstly, from the traditional clientele, then, from budget cuts and finally, from an increase in newly emerging classes of people who need assistance with finding and getting rehabilitation services or rehabilitation technology devices. I am referring to older persons or children of older persons who are confronted with the need for special devices and are often not sure where to go or what to get.

A Source of Problems

An example that I probably have used before is the story of the parent of a child with cerebral palsy who not that long ago counted the number of professionals with whom she and/or her son came into contact during a one month period. She discovered that they met with 37 professionals, a number that is probably high but not totally out of line. I believe that 15 to 25 contacts for a child with a severe disability (quadriplegic involvement with some speech deficit or AAC needs) are not atypical especially if the child needs therapy, speech or AAC services and any one of a number of technical services such as

seating, mobility, computer access, or interfacing and attends a special school. Blessed though we are to live in countries where so many people are available to help our children to cope with disabilities, there is a down side to this situation of nearly continuous professional coverage or CPC.

The down side of the continuous professional coverage (CPC) syndrome is related to a crucial fact that distinguishes pediatric rehabilitation from pediatric medicine. Under the medical model, a patient is treated for a limited time and, in most cases, cured and sent home. In rehabilitation on the other hand, clients live with their disability (pediatric) all their lives. Their disability is an ongoing part of them. There is no professional who can cure or fix them. Over time there will be changes but the basic disabling condition will be with them till they die. This is a truth, a nearly immutable state of affairs which contemporary rehabilitation models do not sufficiently take into account.

Because a person with a disabling condition (or their parents, spouse, caregivers) is constantly confronted with the challenge presented by their environment, they become local experts. Often clients / parents must explain their (child's) characteristics, needs, and obstacles to each new professional. If as is the case of the parent in the example above, a large number of often new professionals

are serving the child, adolescent, and adult throughout different stages of life then this is not a very efficient method of service provision. Each new professional needs to be trained in the specifics of this child and his/her environment. Even if professionals remain constant there are new teachers, new social, cultural, and vocational environments where the consumer must live and work. Each of these new environments requires new adjustments and possible new professional contacts.

The information and support that a child or adult with special needs or disabilities requires are regularly being taught to students who intend to become professionals so they can do for clients what they have been taught in schools or universities.

Inform / Educate the Consumer

The idea that I presented at ECART was to teach each person with a disability or their parents the basic skills/knowledge that they would need throughout their lives. i.e. provide a focused training program that would address the problems they would be likely to encounter. Either the child and/or parents or both would receive ad-

equated training to deal with or resolve the bulk of recurring problems.

Analogies to an approach like this exist with other conditions that are also life-long, such as blindness for which people learn orientation and way finding, and diabetes. Diabetics learn how to balance food intake, medication and exercise routines in a way that allows them to work most effectively. In a similar way people with disabilities should be able to have a basic set of skills and knowledge that will help them deal with their condition without necessarily becoming dependent on continuous professional contact. And rather than have such training occur once in a lifetime it is possible to develop multimedia training packages that address certain specific needs of children, adults or older persons or their caregivers. In not too long a time one could foresee that people would get access to such training materials either at the rehabilitation centre of their choice, but more likely at a library or via a pay-per-view type TV channel where the video-based version of the training can be offered with a minimal

degree of response options. In a much more intriguing version, these training modules could be presented on the world-wide-web or Internet and learning could be interactive.

Figuring out what should be taught to people with specific disabling conditions and/or developing the training and information materials that would allow people to deal with their condition (more) independently will require a substantial effort. It is probably most effective to put these training programs, once tested and perfected, onto tape or other interactive multimedia platforms so that people including persons with disabilities, students, older persons or their caregivers can use the training modules anywhere, anytime, in the format that suits them best.

This of course does not mean that consumers do not need professionals anymore. Professionals will continue to play a crucial role in rehabilitation services. But the roles may change from institution-based to community-based services, from direct service to educational and support roles with occasional primary care/treatment functions in the more complex cases.

§

ISAAC '96 VANCOUVER, BRITISH COLUMBIA, CANADA

"Communication...Naturally!" That's the theme for the ISAAC 1996 Seventh Biennial Conference to take place August 7 - 10, 1996 in Vancouver, British Columbia, Canada. The Scientific Program and Exhibition offer a wide range of topics in the area of Augmentative and Alternative Communication. Both are open to researchers, practitioners, publishers, manufacturers, developers, and of course...AAC consumers!



For more information, please contact the conference secretariat:

ISAAC '96
Vancouver, British Columbia, Canada
August 7 - 10, 1996

- * Presenters addressing a full range of AAC topics
- * Consumer Day Bigger and Better; courses, crafts, idea exchange, and new friendships!
- * Unopposed exhibit & product demonstrations
- * Call For Papers deadline: November 16, 1995!

ISAAC '96
c/o Venue West Conference Services Ltd.
645 -375 Water Street
Vancouver, B.C., Canada
V6B 5C6
TEL: (604) 681-5226 FAX: (604) 681-2503
email: congress@venuewest.com

A Letter from Latvia: Experiencing a New Culture — While Buying Eggs

ALDA STEPRANS

We have a special letter from Alda Steprans who is visiting Latvia for this year. As you will see, she is discovering a number of "disabling" conditions in Latvia.

My family and I are fortunate in being able to spend this school year in Latvia, a country on the eastern coast of the Baltic Sea. Latvia regained its independence in 1991 after 50 years of Soviet domination. Life here remains very interesting politically, socially and culturally and almost constantly offers many challenges. Living here, I am frequently reminded of the disruptive effect a different culture has on communication.

Although my husband, my children and I all speak Latvian, we are amazed at the misunderstandings which can arise as a result of different interpretations of language and culture. The first time I bought eggs here, I was given 10 eggs in a plastic bag. When I asked for an egg carton, the shop keeper looked at me, and responded as though I were from another planet. I had not been aware that shoppers going to the market here must bring along their own jar or plastic egg carton if they are concerned about getting their eggs home unbroken. I felt quite silly and childish at not having known, but also at having been spoken to in such a derogatory tone of voice.

Shopping for eggs in an unaccustomed way is, of course, a minor variation in lifestyle, but it is one of many changes to which I have had to adapt. I have bought a plastic egg carton and feel much more content now that I can safely carry my purchase home. I approach the egg sellers with a new confidence and they no longer reproach me for my ignorance. In retrospect, it seems foolish that such a little incident could have affected me so.

Although my husband, my children and I all speak Latvian, we are amazed at the misunderstandings which can arise as a result of different interpretations of language and culture.

All of these little adaptations I have had to make, living in a new culture with different rules, remind me of how people with chronic illnesses must also have to change, adjust and alter their culture in order to fit in with the rest of society. These changes are not always as minor as the ones with which I have been faced and affect not only the handicapped individual, but that individual's family and friends as well. Nancy Gibbons' article about Elizabeth in the last issue of **Communicating Together** is a good example of this. She reminds us of the many choices to be made in life,

some that are agonized over for a long time, especially when a culture or situation is unfamiliar or different, as it tends to be when chronic illness occurs. As Nancy points out, there are many different paths that can be taken in striving towards the destination of dignity and independence we each strive for.

I strongly agree that we must respect each person's, each family's individual paths in reaching that goal. In Canada, we still far too infrequently see severely chronically ill people taking part in the community at large. Although many buildings are now wheelchair accessible, that accessibility is often only symbolic in nature. I have taken our residents on many out-trips and know what it is like to struggle on narrow, steep ramps, with corners that do not permit easy turning of the wheelchairs. Our elderly volunteers are often unable to push the heavy chairs up these ramps. The automatic doors often close before the wheelchair has passed through them. The elevators are often crowded with other visitors and in most instances do not permit more than one wheelchair at a time, so that if a group of wheelchair dependent people wants to stay together, it may take half an hour of an outing just to get 8 residents up to an exhibition and another half hour to get them back down. The residents never complain, though. They welcome any change and the company of the volunteers is always pleasant.

And yet, seeing what life is like here in Latvia for disabled/handicapped people, I am reminded about how very fortunate we are in Canada. In Latvia, most physically handicapped people are literally stuck on their beds in one room of a small apartment. These apartments are small - usually one or two rooms, a bathroom and kitchen. The bathroom and kitchen may be shared by two or three families. Wheelchairs are more common now, thanks to international aid. However, few buildings have elevators, there are no wheelchair ramps on sidewalks, and there are certainly very few buildings or stores with wheelchair access.

I have not yet had the opportunity to visit a chronic care hospital here - although I hope to soon - but I have already heard about the terrible conditions I can expect to find there. Sheets get changed infrequently, for lack of soap, linen and laundry facilities. Family members often must take the laundry home to wash. Physical care is scarce. Workers are paid so little that they often look for other work. Nurses get paid 30 - 40 Ls (about \$100) a month and even doctors, whose salaries are twice as high, have great difficulty dealing with a cost of living comparable to that in Canada. Hospital food consists of very basic porridges, gruels and potatoes. The government says it has no money for more. Family members may bring in more substantial meals, but many of the people who live in such places have no family.

And yet, the caregivers I have met do care and are eager to learn with the hope of being able to do more. I have recently become involved with an organization called "Rupju Berns". This term is impossi-

ble to translate directly, but it means roughly a child who requires concern, worry, or care. I am enjoying working with this group, because it has been formed by the parents of mentally and physically handicapped children in Latvia. They are working very hard to obtain rights for their children, who have been and still are very excluded from the mainstream of society. At the moment I am helping one branch, here in the capital, Riga, to set up a day care centre for mentally handicapped adolescents and young adults. Most of the involved parents work elsewhere, but have found the time and energy to lobby, to look for a suitable building, to search for heating, furnishings and staff for the centre. They understand that their children are capable of learning how to care for themselves and how to behave in the society around them.

Most of these young adults presently spend all day at home. Many of them are only mildly handicapped and the centre will take this group first. Next summer, the day care hopes to gain access to the first floor of their selected building. It does have wheelchair ramps, but only because the building was a day-care centre for small children who required strollers. However, the entranceways require rebuilding to permit entry of larger chairs.

Finding money for these renovations is always a challenge in such a poor country. The centre hopes that by next fall, it will be able to accept more severely, wheelchair dependent handicapped adolescents and young adults. This is a very interesting undertaking and I wish these parents well. There are no programmes in Latvia that teach special education, so it will be difficult to find experi-

enced staff. However, as I mentioned before, most people here are very eager to learn and I believe that this environment will at least be a caring one.

Although life here is very interesting, I greatly miss my friends, neighbours, co-workers and the residents I have cared for. Not a day goes by when I do not wonder what they are doing, how they are managing, what new concerns and joys they are sharing. I will no doubt continue to adapt, learn, try to communicate and understand the new culture around me. We should not let the challenges of a different culture frustrate us. We have to learn to co-exist, accept and enjoy what is good about it and try to understand what it is we find hard to accept, so that we may grow from our experiences. Once I have seen more about life for the handicapped here, I will be sure to write and let you know about it.

§

Young lady in late teens, currently attending special school, would like to exchange letters only with other interested person or persons in order to improve communication skills.

Enjoys cooking, sewing, crafts, drawing pictures, listening to music, etc. Please write to:

Shelley Mathers
Box 1149
HAILEYBURY, Ontario,
POJ 1K0

Responding to "What is Your Latest Thinking on Bliss?"

SHIRLEY McNAUGHTON

Recently a colleague asked me to send her my current perspective regarding Blissymbolics. The following comments on the system of Blissymbolics and its place in augmentative and alternative communication (AAC) are based on my response.

I find myself thinking a lot about Bliss as I work on my thesis. I see the value of Bliss more and more as a transition "language" between pictures and print, for all who can achieve literacy, and a longterm language for those who cannot become fluent in spelling. I am beginning to treat more seriously the distinction between spelling and reading, discovering that there are those who can use spelling very competently for communication, but who still have serious reading difficulties.

Planning a Communication, Language and Literacy Program

My ideal program would be an initial introduction to pictures at as young an age as possible, with ongoing evaluation as to when the child is ready to transfer to pictographic Blissymbols. Once the child is using some pictographic Blissymbols, I would begin adding

ideographic Blissymbols to their display, and I would follow this with the teaching of letter strategies — beginning with the use of initial letters, then adding other letter strategies as the child becomes aware of their role in decoding. I would add whole words to the child's communication display whenever the word is known and can contribute to effective communication.

It is the language structure and scaffolding that Bliss provides that I believe is one of its important strengths.

I would relax on whether the plural, past tense, possessive, etc., is symbolized by Bliss or by orthography — using whatever the child latches onto and uses. My goal would be emphasizing the structural aspects of Bliss in the *introduction* of symbols and relating this to orthography whenever the child can grasp the concept. I would not worry if there was a mix of pictures, Bliss and print, so long as the structural aspects of Bliss were consistently adhered to. It is the language structure and scaffolding that Bliss provides that I believe is one of its important strengths. This means that I would want the child to be aware of the past tense symbol even if he/she preferred to use "ed" after the

symbol or word. The combine, opposite meaning, similar to, and sounds like, strategies would be high on my list for mastery even while print was being worked on.

I believe we should concern ourselves with (a) the child's development of conceptual strategies to compensate for having to communicate in a cumbersome way (not having the system of choice - natural speech) and (b) the child's development of language in order to gain a metalanguage competency and a mastery of print in as many forms as possible — spelling, reading, writing. This means a strong emphasis on cognitive skills and phonological skills — always being aware that proficiency in the phonological domain is likely to be an area of difficulty. The development of both areas requires innovative teaching.

My desire to maintain an international standard for the system of Blissymbolics is as strong as ever, but I do *not* believe it should be our concern as we are working with children who are developing within an emerging literacy program! I believe Blissusers who progress to print will appreciate the international capability of Bliss all the more after they have joined our literate community. They will have a real edge on the rest of the world as BlissNet becomes used between language groups and they can return to their first language, Bliss, for interacting internationally.

So, what I am emphasizing is that the needs of the learning child must come first. I firmly believe that Bliss has a strong contribution to make and that we should not be thinking of which system an individual should have, but rather, when should the three types of systems be provided to the child. Pictures, Bliss, orthography, each offer different strengths to the developing child when introduced at the appropriate stage of development. All of them are important. Pictures offer immediate recognition and reduced cognitive demands, freeing attention for communication — important when the child is just learning what communication is all about; Blissymbols offer an explicit language scaffolding, preparing the way for independent mastery of what will always be a challenge — trying to replicate the accomplishments of speech; orthography offers the ability to generate any utterance and to access all of the opportunities afforded by literacy.

Thanks for asking where I am at, and reading these thoughts I have put to keyboard. My biggest concern is the ever present bandwagon! In the past, we've watched helplessly as people have tried to give Bliss to all their clients, whatever their developmental level, and then observed many individuals fail. We're now aware of pictures and Minspeak icons being favoured for entire caseloads in the same way.

Looking Again at Language

Emergent literacy principles guiding a child's program are providing an excellent context for literacy learning for AAC users; however, if no attention is given to

the learning to be derived from the different types of symbols which can be used, I believe the child's literacy program falls short. I was very pleased to see the research report by David Beukelman and Beth Ansel in the June, 1995 edition of our journal, *Augmentative and Alternative Communication* — "Research Priorities in Augmentative and Alternative Communication" (p.131- 134). The paper described the research priorities arrived at during a workshop held by the National Institute on Deafness and Other Communication Disorders (NIDCD), Bethesda, Maryland, USA. The first priority was to study the impact of AAC technologies on the development of communication, language, natural speech, and discourse skills of persons with severe communication disorders. Included with it was a questioning of "how AAC users learn to represent language" and "the impact of AAC use on syntactic learning". Interest was shown in "the symbol system used and 'grammar' or the relationships among the symbols" and in the "influence of various AAC strategies and features on literacy development". It was so satisfying to see research attention being directed to the language domain. This is the kind of study that will strengthen our knowledge as to the role to be played by Blissymbolics. I'm convinced it's an important one!

BlissNet

Lastly, BlissNet is my current focus, because it offers a computer mediated telecommunication opportunity for those who have benefitted from Bliss in their growing years.

They can now socialize as often as they wish within a broad community. They can help others who are currently using Bliss — whether they are beginners, longterm users, or on their way to literacy. BlissNet also promises an international forum for Bliss users. I welcome BlissNet more and more as I become increasingly aware of the fragile health and the energy limitations of many of our Bliss experts! BlissNet offers a way to keep in touch when the travel that accompanies face-to-face meetings becomes too demanding. Full participation in the electronic highway can't come soon enough! We're doing our best to ensure that BlissUsers will be among its most frequent travellers.

The needs of the learning child must come first.

With BlissNet, we have a new domain for this system for which I have such high regard. We can be as flexible with Blissymbolics as need be, in applying it within an individual's communication and literacy program. On the other hand, we can appreciate all the more its international capabilities, as designed by Charles K. Bliss, for the worldwide communication the system affords.

Remember, an invitation is always open to those who wish to share their ideas re any AAC graphic representational system. Please send us YOUR "latest thinking on " for SymbolTalk!

And watch for more information on BlissNet in the March issue.

CONTENTS

2	EDITORIAL As Abilities Change	PAUL MARSHALL SHIRLEY McNAUGHTON PETER LINDSAY
4	FEATURE Living with Someone with Huntington's Disease	ELEANOR CORNISH
6	KARI'S SKALLAGRIGG — PART THREE	KARI HARRINGTON
8	CONSUMING TECHNOLOGY A Glimpse Into the Future	ROBERT HAAF
11	TEACHING AND LEARNING As Abilities Change, Does Communication? Living with ALS Living with Parkinson's Disease	TRACY SHEPHERD JOHN WILKINSON KEITH EBBINGHAUS
13	PERSPECTIVES Maintaining Communication	ESTELLE KLASNER
14	Different Therapeutic Focuses	TARA SCOTT
15	AS COMMUNICATION CHANGES If You Don't Use It, You Lose It. When Communication Fails	BRIAN PAMPLIN ALDA STEPRANS
18	CONTEXTS Rehabilitation as Self Service	GEB VERBURG
20	READERS WRITE Experiencing a New Culture — While Buying Eggs	ALDA STEPRANS
22	SYMBOLTALK Responding to "What is Your Latest Thinking on Bliss?"	SHIRLEY McNAUGHTON

Communicating Together established in 1982, is published quarterly since 1991 by *Sharing to Learn*. Its mandate is to provide a means of sharing the life experiences and communication systems of augmentative communicators with other augmentative communicators, their families, their communities and those who work with them.

Co-editors:

Peter Lindsay & Shirley McNaughton

Associate Editors:

Suzanne Clancy, Robert Haaf, Paul Marshall, Colleen McGaffey, Nola Millin, Brian Pamplin, Tracy Shepherd, Alda Steprans, Geb Verburg.

Editorial aid: Barbara Reid

Administrative Assistance: Bob McNaughton

Subscriptions: Liz Goldstein

Desk Top Publishing: Peter Lindsay

Typesetting & Printing: Central Printing Services, Guelph, Ontario.

Subscription Rates per Year:

Canadian - \$25.00 Cdn;
U.S. - \$23.00 U.S.;
Outside North America - \$30.00 Cdn.

ISAAC Members' Rates

Canadian - \$20.00 Cdn
U.S. - \$17.00 U.S.
Outside North America - \$26.00 Cdn.

Direct correspondence regarding

subscriptions, articles, advertising, subscription support, address changes and bulk mailing to:

Communicating Together

Suite 215, 3-304 Stone Rd. West
Guelph, Ontario, Canada N1G 4W4

Phone enquiries: 519-763-1757

Fax: 519-763-6682

Email: plindsay@oise.on.ca
smcnaughton@oise.on.ca

Cover: The cover shows Eleanor and Bruce Cornish as they talk together

The publisher offers *Communicating Together* as a vehicle for editors, associate editors and contributing authors to present their perspectives on augmentative and alternative communication. The views expressed are not necessarily those of the publisher although the human interest, consumer involvement and international perspective are.

The contents are copyright.

Communicating Together is an affiliated publication of the International Society for Augmentative and Alternative Communication (ISAAC).

Second Class Mail Registration No. 7093
GST Registration No. R130220619
ISSN No. 822-0638